

A NEWSLETTER OF THE NEWBORN SCREENING PROGRAM AND THE NEWBORN SCREENING LABORATORY UTAH DEPARTMENT OF HEALTH

Newborn Screening Basics

Back to Basics

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A brief history of 7 newborn screening

Did you Know?

- In 2004 there were 51,278 newborns screened in Utah.
- Out of these specimens 812 were abnormal.
- Out of the specimens that were abnormal
 42 needed treatment.

The Newborn Screening Program is changing! We recently hired new staff and are looking forward to many changes in 2005 as we expand newborn screening. With all the change, it is helpful to look at what remains constant. The newborn screening program remains dedicated to providing timely and accurate screening results for all babies in Utah. The newborn screening process is a team effort, and you are part of that team as we work together to achieve our goals.

We hope that improving newborn screening in your practice is also one of your goals for 2005. To help, this

issue of the newborn screening newsletter is devoted entirely to "the basics" of newborn screening, focusing on the problems we see occurring most frequently. As you read this newsletter, pay attention to the basic things you may be missing and then set a goal to improve newborn screening.



It's Not JUST a PKU

William Shakespeare wrote "A rose by any other name would smell as sweet." But when it comes to newborn screening, what you call it can make a big difference.



PKU was the first disease that was able to be detected by newborn screening. Because of this, many people refer to the entire newborn screening panel as a PKU. But PKU is only one of the diseases screened for on the newborn screening panel. Calling the newborn screen a PKU causes communication problems between doctors, nurses, families, and the newborn screening program.

To prevent confusion, refer to the newborn screen by its correct name, a newborn screen.



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Orion 10/11/2004

"The newborn screening program provides free training by a registered nurse. Call (801) 584-8260 to schedule a training at your facility today!"



Tired of Rejections?

It happens to the best of us. We call it an unsatisfactory specimen. You call it rejection. Whatever the name, un-testable specimens mean more work for you, and inconvenience for the family, and most importantly delay screening for the baby.

We do not like to reject specimens, but testing an unacceptable specimen can yield inaccurate results. Once a specimen is determined to be "unsatisfactory" a letter and a replacement collection form is sent to the provider who drew the specimen. A letter is also sent to the mom to alert her that a repeat specimen is needed for her baby.

It is important that the specimen be redrawn as soon as possible. Screening only works if the condition is detected early. The faster you collect the repeat specimen, the sooner we can get it tested.

When the unsatisfactory letter comes to you, it will have a reason for rejection listed on the mailer. Use an unsatisfactory specimen as a learning experience. Review the reason for rejection, learn what mistake was made, and then collect a better specimen next time.

With practice (and experience) you will draw great specimen every time.

How to Collect a Perfect Specimen... the First Time.

Here are a few tips to help you collect a great screening specimen the first time around.

Use the right tool. A poor lancet will make your job more difficult. We recommend that you use a lancet that is specifically designed for newborn heel sticks. The lancet should be at least 2 mm in length. Call the newborn screening program for a sample of lancets that we find work well.

Do not use capillary tubes for specimen collection. They can scratch the paper and interfere with testing. A heel stick is the best way to get the blood onto the filter paper.

A warm foot makes blood draws easier. Make sure the baby's foot is warm before you draw blood, especially at this time of year. You can purchase special

warming devices made just for babies, or you can use a glove as a warm compress. Simply fill the glove with warm water, tie it off, and apply it to the baby's foot. Be careful the water isn't too hot or you may burn the baby.

Protect the filter paper. Nothing should touch the filter paper except blood. Keep your hands away from the paper while you fill out the form. During the heel stick, be careful that the baby's heel does not touch the filter paper.

Let it dry. Specimens should air dry for at least 3-4 hours, in a horizontal position. We have special drying racks that you can use. To order a free drying rack, call us at (801) 584-8256.

Get it in the mail! Specimens should be mailed within 24 hours of collection.

Help is on the way!

Does the thought of collecting a newborn screen make you sweat? Do you find you are recollecting a lot of specimens? Do you have new staff?

If you answered yes to any of these questions, you might benefit from a newborn screening training.

The newborn screening program provides free training by a registered nurse. We can come to your clinic during a staff meeting, a lunch break, or any other time. Call (801) 584-8260 to schedule a training at your facility.

You Rejected it for WHAT?!

"Making mistakes simply means you are learning faster."

~Weston H. Agor

When it comes to newborn screening, making mistakes is the fastest way to learn. An even better way is to learn from the mistakes of others.

Here are the top reasons why specimens are rejected, and some possible mistakes that could have been prevented during collection.

Circle torn, scratched, or wrinkled. This is the most common reason specimens cannot be tested. When the filter paper is wet, it is the most vulnerable to tears, scratches, and wrinkles. Remember that nothing can touch the filter paper except blood. When collecting the specimen make sure you have a firm grasp of the baby's foot. Allow a large drop of blood to form. Then touch the drop of blood to the paper, taking care not to let the baby's heel touch the paper. Once the circles are completely filled. carefully put the form in a safe place while you bandage the baby's foot. Let the specimen air dry horizontally on a

Blood not soaked through. This happens when the blood does not completely soak through to the other side of the filter paper. This can happen for several reasons. If the filter paper is

drying rack in a safe location.

touched, oil from the hands or powder from gloves can cause a barrier to form on the filter paper. Nothing should touch the filter paper but the blood. Also, a small drop of blood does not soak through as well as a larger drop of blood. Allow a large drop of blood to form before applying it to the filter paper. One large drop of blood will be more successful than many small drops.

Blood clots. This happens when the blood clots before being applied to the filter paper. If it takes a long time to collect the specimen, blood clots can result. To avoid this make sure the baby's foot is warm and you are using a good lancet to get maximum blood flow. Completely fill each circle with blood before moving to the next circle. Air dry the specimen in a horizontal position to prevent blood from pooling and clotting.

The form expires? Newborn screening forms expire just like any other medical device. If the form is expired the specimen will be rejected, no matter how perfect the blood draw is. Check the expiration dates on each and every form. The expiration date is found on the left side of the form, across from the sample collection date.

Niels Bohr said "An expert is a man who has made all the mistakes which can be made in a very narrow field." Learn from the mistakes of others, and become a newborn screening expert!



Madux 9/15/2004

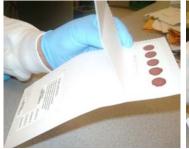
"An expert is a man who has made all the mistakes which can be made in a very narrow field."

-Niels Bohr

New Postal Regulations

New postal regulations require specimens to be double enveloped when mailed. The newborn screening program recently added a barrier flap to specimen forms to satisfy this regulation.

The barrier flap is the piece of cardstock located on the back of the form. Fold this flap up and over the specimen, exposing a biohazard symbol. Then place the covered specimen in an envelope.









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Ean 6/27/2002

"You should always have miscellaneous forms on hand. Determine how many your practice uses, and keep a supply in stock"



Griffin 4/30/2002

Filling out the form

National laboratory standards state that a specimen can't be tested without proper specimen identification and a collection date. If the information isn't on the form, we can't test the specimen, which means more work for you in the long run.

Everyday, specimens are received at the state lab with missing or incomplete information. Are you filling out the forms correctly? Grab a newborn screening form, and then read the tips below to make sure you are filling out everything correctly.

If it is shaded pink, it is important! Everything that is in pink is absolutely necessary before we can test the specimen. Make sure there is correct information in every pink box.

Specimen collection date. We can not test the specimen without a collection date. Without a collection date, testing is delayed until we can find it. Save time by writing in the date on every specimen you collect.

Is it a girl or a boy? The first question any new mother gets. It is also important to the newborn screening program. Too often, the first and second specimens differ. One says it is a girl, the other a boy. Make sure you are marking the correct sex of the baby.

Birthplace/Hospital. Initials can be tricky. Is AVH Alta View Hospital or Ashley Valley

Hospital? Is DMC Davis Medical Center or Delta Medical Center? Write out the complete name of the hospital if initials are confusing. If the baby was born out of state, write "out of state" as the birthplace.

Adoption. Is this baby being placed for adoption? Is this baby already adopted? Then mark the adoption box. All information is kept confidential.

The mother's information is just as important as the baby's information. We need all this information to help us identify the baby. Make sure her name, address, birthday, and phone number are correct.

Medical home. This is the place where you write down who should get results. Ask yourself "if this specimen is abnormal, who should the newborn screening program call?" Please make sure this information is as correct and complete as possible. Write in the full name of the doctor. Include a phone number and address if you have it.

Check, Check, Check. Get in the habit of triple checking the information on the form. Check to make sure everything is right before you draw the blood. Then after you draw the blood, check again for missing information. Finally, after the specimen is dried, before you put it in the mail, check again one last time. It saves time in the long run. 467-2190

Using Miscellaneous Forms

Miscellaneous forms are replacement forms that can be used if you make a mistake, or if the mom forgets the second screening specimen. The best part is they are free to providers. However, help us keep newborn screening costs down by using them only when needed.

You should always have miscellaneous forms on hand. Determine how many your practice uses, and keep a supply in stock. You can order miscellaneous forms by phone, fax, mail, or email. Call (801) 584-8256 to get an order form.

Remember, these forms expire, so please rotate them. Check the miscellaneous forms you have in stock, and destroy any outdated forms. The expiration date is found on the top left of the form, across from the specimen

collection date.

Every miscellaneous form that you use needs an original birth record number (also called a kit number). Where can you get the birth record number? The hospital where the baby was born keeps that information in the newborn screening log book. You can also call the newborn screening program to get the number. Once you have the number, cross out the miscellaneous kit number, and write in the birth record number.

When using a miscellaneous form, you will need to mark which test you want. Under the "test requested" box mark first screen if the miscellaneous form is replacing the first screening form or second screen if the miscellaneous form is replacing the second form.

Just for Hospitals & Midwives

According to Utah law, first specimen collection is the responsibility of the institution or practitioner primarily responsible for delivery of the baby (R398-1-4). While the procedure is uniform for collecting both first and second specimens, there are some important considerations that hospitals and midwives who collect first specimens should know.

Timing of the first specimen is very important. Specimen collection that is too early or too late can alter screening results and impact the health of the newborn. Collect specimen 48 hours after birth or 4 hours before discharge from hospital.

Do not delay mailing specimens. For liability and risk management you might want to consider sending specimens by courier. Check with your facility to find the most effective and efficient way to get specimens to the state lab quickly.

Educating the parents about newborn screening is an important task. The institution who collects the first screening specimen is responsible for this task. (R398-1-7). Use the newborn screening brochure as an educational tool. Explain to the parents that newborn screening is important to make sure their baby does not have rare, but treatable diseases. Instruct the mother to bring the second newborn screening card with her to the baby's two-week checkup for another specimen collection.

If you fill out the second screening form, do not fill out information that may change after the baby goes home. For example, often baby's last name or medical home changes after discharge. Only fill in information that will not change, such as sex, birthday, and birthplace. If identification of the second screening form is a concern, write the baby's name on the cover sheet or the envelope instead of the screening form

When writing in the medical home, use the full name of the doctor, as there are many doctors with the same last name in Utah. Do not leave the medical home blank. If the family has not decided on a pediatrician, write "undecided" and make sure mom's contact information is current so we can locate a doctor if needed.

A newborn screening handbook is available to assist you in collecting newborn screening specimens. This handbook is a great reference and provides instruction on ordering kits, submitting specimens, completing the demographic portion of the newborn screening form, and more. This handbook is free to providers, hospitals, and midwives. Call (801) 584-8256 to have a handbook sent to you today.

If the specimen is abnormal, the newborn screening program uses the information on the first screening form to locate baby and arrange for more testing. Thank you for your diligence in providing quality specimens with accurate and complete information.



Dallin 12/14/1997

"The first screening specimen should be collected 48 hours after birth, or 4 hours before discharge from hospital"

Just for Newborn ICUs

Because of the fragile nature of the infant and underlying medical problems, newborn screening for infants in an intensive care unit requires special considerations. Here are some guidelines to consider when drawing a newborn screen on an infant in a neonatal intensive care unit.

Blood transfusions alter newborn screening results. When possible, collect the first newborn screening before a transfusion is given. If it is not possible to collect the screen before a transfusion, draw screening specimen after the transfusion. Be sure to note on the screening

form that the infant received a transfusion *before* specimen collection. Mark the transfusion box (located underneath "birthplace/hospital" on the left side of the form) and write in the date the transfusion was given. This information helps the newborn screening program interpret screening results and recommend specific appropriate follow-up procedures.

The timing of the second screening specimen is also affected when an infant has received a blood transfusion. For a valid second screening specimen, collect the specimen 7 days after the last blood





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Oker 7/1/2004

"When you call to confirm the appointment, remind the parents to bring the second screening form with them"



Grace 10/26/2000

transfusion. Mark the transfusion box and write in the date the last transfusion was given.

Transferring sick babies between hospitals causes potential for a missed newborn screen. Utah law states that if the baby is transferred to another institution prior to 48 hours of age, the receiving hospital is responsible to collect the screening specimen (R398-1-4). If you are unsure if screening has been done, or if you are missing newborn screening results, call the newborn screening program at (801) 584-8256.

Premature and sick babies often have abnormal screening results. Please mark the "premature/sick" box (located underneath "birthplace/hospital" on the left side of the form) to help us interpret results and provide appropriate follow-up.

Who is the medical home for a baby in the newborn ICU? This is a tricky question. A medical home is an approach to providing health care services in which a child receives quality care from a pediatrician or physician whom the family trusts. While the infant is in the newborn ICU continuous communication with the medical home should occur. For this reason, the "medical home" for an infant in a neonatal intensive care unit is the NICU. When filling in the medical home information on the screening card, write the name of the NICU.

Do not collect the screening specimen from a line that is used to deliver alimentation or drugs. The best way to collect a screening specimen on any infant is by heel stick. If a heel stick is contraindicated, blood may be applied to the filter paper with a needle or syringe. Allow a drop of blood to form on the tip of the needle or syringe. Touch the blood to the filter paper, taking extreme care not to scratch the paper with the tip of the syringe or needle.

Discharge from the NICU before abnormal screens have been properly followed up can cause problems. Keeping a log in the NICU of discharged infant's medical homes can help with timely follow-up of these infants.

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Thank you for your diligence in providing quality specimens with accurate and complete information.

Just for Medical Homes

The medical home is primarily responsible for collecting the second screening specimen. Here are some common concerns unique to medical home and second specimen collection, and some hints that may help your practice.

Do you have a problem with moms forgetting to bring in the screening form to their appointments? It helps to remind the mom to bring in the form the day before the appointment. Some practices make this a part of their confirmation appointment call. But just in case the mom still forgets, you should have a supply of miscellaneous forms on hand. See page 4 for more information on using miscellaneous forms.

Are you collecting the specimens at the right time? Second specimens should be collected between 7 days and 28 days of life.

If the second specimen is collected too early it can interfere with screening results. If the second specimen is missed and the infant is older than 28 days the specimen can still be collected; however, the sooner the specimen is collected the better.

Are you getting the results of your screens? To get results, the doctor's name must be on the form. Use the full name of the doctor, as there are many doctors with the same last name in Utah. Include a phone number and address. Some practices use an address stamp to save time.

Who fills out the form? Some practices have the parents fill out the information on the screening card. We do not recommend this, as they might touch the filter paper. They also might not understand some of the wording, such as "medical home" on the

screening card. We recommend that while the baby's foot is warming, you take that time to fill out the card with the mom's help.

Do you throw away the instruction sheet? This sheet has the baby's birth record number (or Kit #). If you write the date of collection on the form and save it in the medical chart you will have a record of when the specimen was drawn and on what card.

Do you have a newborn screening handbook in your practice? A newborn screening handbook is available to assist you in collecting newborn screening specimens. This handbook is a great reference and provides instruction on ordering kits, submitting specimens, completing the demographic portion of the newborn screening form, and more. This handbook is free to providers, hospitals, and midwives. Call (801) 584-8256 to have a handbook sent to you today.

Thank you for your diligence in providing quality specimens with accurate and complete information.

A Brief History of Newborn Screening

Sheila* is retarded. Kammv*

was spared because of new

Retarded Children Can Be Helped

National Association for Retarded Children

1961 Poster Children

SUPPORT YOUR UNIT, NATIONAL ASSOCIATION FOR RETARDED CHILDS

medical research.

In 2004, 42 Utah infants were identified and treated for a disease identified through the newborn screening test. Sometimes newborn screening might seem routine but to these 42 families, newborn screening was a routine test that saved their baby's life.

Newborn screening has a relatively recent history, which began with the disorder PKU. Prior to 1953, screening for PKU was not feasible because there were no treatment options available. For screening to be an

effective tool, there needs to be a treatment available. In 1953 Horst Bickel of Germany discovered a treatment for PKU. The work of Horst Bickel provided hope that PKU could be prevented by screening. If individuals with PKU could be identified and treatment started before they developed symptoms of the disease, mental retardation could be prevented.

Without a screening program, a diagnosis of PKU meant a future of mental retardation. Because of the recessive

genetic inheritance of PKU, affected families were faced with multiple disabled children. After a treatment was discovered all infants born to a family with a known history of PKU were treated immediately after birth. This resulted in the early treatment of a newborn only after the sacrifice of an earlier retarded sibling.

In 1961, the poster children for the

National Association for Retarded Children were two sisters, both of which had PKU. The older sister was not diagnosed with PKU until mental retardation had set in. After the family was identified at risk, the younger sister was started on treatment at birth and avoided mental retardation. The touching picture emphasized a need for mass screening program to ensure health of all babies, regardless of birth order.

That same year, in 1961, Dr. Robert

Guthrie developed a simple screening test able to be performed on a dried blood specimen applied to specially designed filter paper. This test provided a simple cost effective way to screen all infants for PKU. Dr. Guthrie later stated that the newborn screening test "was a very simple idea, like inventing a safety pin, but it made possible the testing of every newborn baby before leaving the maternity hospital".

After the initial development of the PKU test, Dr. Guthrie began research on other screening tests using

the same techniques for specimen collection. Today there are screening test available for over 30 disorders, all using the same heel stick procedure and filter paper designed in 1961.

1n 1965, Utah passed newborn screening legislation mandating newborn screening for every infant born in the state of Utah. And, as they say, the rest is history.



Easton 1/28/2003

"Newborn screening was a very simple idea, like inventing a safety pin, but it made possible the testing of every newborn baby before leaving the maternity hospital"

-Dr. Robert Guthrie



Dane 9/14/2000

A newsletter of the Newborn Screening Program and the Newborn Screening Laboratory Utah Department of Health

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WE'RE ON THE WEB! http://health.utah.gov/newbornscreening



In today's busy health care environment it is nice to have resources available to ensure quality specimen collection. Here are some resources available to you. Please call (801) 584-8256 to order any of these free tools.

- Specimen drying racks
- Parental Educational Materials
- Parental Educational Materials in Spanish
- Newborn Screening Practitioner's Manual
- Newborn Screening Handbook
- Training provided at your facility

Newborn screening is a team effort. We appreciate your efforts to collect adequate and timely specimens.

Utah Department of Health Division of Community and Family Health Services Newborn Screening Program Box 144710 Salt Lake City, Utah 84114-4710 PRSRT STD U.S. POSTAGE

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